



### THE VIRGINIA TBIMS TEAM

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### First Annual TBI Caregiver's Conference Provides Support to Families

By: Taryn Stejskal

Many family members, especially parents and spouses, take on a primary caregiving role after a family member sustains a brain injury. Recently, shorter lengths of hospital stay and reduced community resources have only increased the burden placed upon family members serving as caregivers. Yet, many caregivers are often overlooked, underprepared, and ultimately, provide care at a cost to themselves. Caregivers do best when they are educated about brain injury, supported emotionally, and have the skills to provide care to their loved one.

After a family member is injured, many people do not see themselves as caregivers. Instead, a person may see themselves as rising to the occasion to care for a child or a spouse, making good on the "worse" part of the "for better for worse" promise. However, providing any amount of unpaid care or assistance to a family member does qualify a person as a caregiver. Recent research suggests that most people will become a caregiver at some point in their lives.

As a caregiver, you are certainly not alone. In order to meet the needs of family members providing care to survivors of brain injury, the first annual National TBI Caregiver's Conference was held in Williamsburg, VA on Saturday June 7, 2008. VCU Medical Center partnered with the National Resource Center for TBI, Brain Injury Services (BIS), Brain Injury Association of Virginia (BIAV), University of Alabama at Birmingham, and Memorial Hermann/TIRR in Texas to sponsor this conference. As a result of the collaboration, many leaders in the brain injury field from across the nation, including Alabama, Texas, Maine, North Carolina, Ohio, and Virginia traveled to

Williamsburg to give presentations on recovery and caregiving.

The conference began with two keynote speakers. Beverly Bryant, an internationally renowned speaker and survivor, shared her personal experiences and insightful humor to describe the obstacles she has encountered along her healing journey. She is the author of *In Search of Wings* and *To Wherever Oceans Go*. Debbie Leonhardt also spoke to the audience about the importance of faith, maintaining life balance, and the ABCs of caregiving.

In addition to the keynote speakers, many presenters covered topics related to behavior management, safe driving, return to work and school, effective advocacy, rebuilding relationships, emotional recovery, avoiding burnout, and how the brain works. The conference sponsored a lunch and reception which allowed caregivers, family members, and survivors to network with one another and share experiences.

Given the overwhelmingly positive feedback from participants, planning for the second annual National Caregiver's Conference is currently underway. In 2009, a track will be added to address the specific needs of survivors.

The conference will take place on **Saturday June 6, 2009** at the Williamsburg Hospitality House. We look forward to seeing you there!

For more information, please contact Linda Nowsherwan:

✓ [lee@braininjurysvcs.org](mailto:lee@braininjurysvcs.org)

✓ 703 451-8881

## Life and Work After TBI

### *Energize and Fight Fatigue After Brain Injury!*

Fatigue is often a chronic problem after a brain injury. The injury itself is the primary cause, but there are behaviors and life-style choices that can make the problem worse.

People often fall into three categories after a brain injury: **Sleepyhead, Supercharged, or Somewhere-in-Between.** Being tired all the time or falling asleep during the day can make it difficult to increase your daily activities or go to work. Being restless and up at night can be unsafe and make restful sleep difficult. Every brain injury is unique, and sleep and fatigue problems improve at different rates for each person during recovery.

Remember, **fatigue is worsened by:**

- ✦ Staying up too late
- ✦ Doing too much or trying to do too many things at once
- ✦ Tension and stress
- ✦ Commotion
- ✦ Frustration
- ✦ Pain
- ✦ Poor eating habits
- ✦ Certain medications
- ✦ Use of drugs or alcohol

The good news is that there are some ways to control these factors, energize, and reduce fatigue. Here is a checklist of fatigue-related problems. Check all that are true about you.

1. **I FEEL RESTLESS AND CAN'T KEEP STILL**\_\_\_\_\_
2. **I STAY UP MUCH OF THE NIGHT, TOSSING AND TURNING**\_\_\_\_\_
3. **PEOPLE ARE ALWAYS TELLING ME TO "RELAX" OR "SLOW DOWN"**\_\_\_\_\_
4. **I WAKE UP EARLY AND CAN'T GO BACK TO SLEEP**\_\_\_\_\_
5. **I CAN'T KEEP MY EYES OPEN DURING THE DAY TIME**\_\_\_\_\_
6. **I FEEL TIRED ALL THE TIME**\_\_\_\_\_
7. **I STAY SLEEPY EVEN IF I NAP OR SLEEP ALL NIGHT**\_\_\_\_\_
8. **I WANT TO SLEEP WHEN EVERYONE ELSE IS AWAKE**\_\_\_\_\_

(Continued on Page 3)

## Mark Your Calendar!



- ◆ **Event:** T.G.I.F.
- ◆ **Location:** Belmont Recreation Center, 1600 Hilliard Road in the Lakeside area of Henrico Co.
- ◆ **Description:** the local departments of recreation & parks host this monthly social event for survivors of brain injury, ages 18+
- ◆ **Contact:** Call Kariayn Smith, 804-501-5135, for more information and/or to be placed on the mailing list for monthly reminders.
- ◆ **Event:** Richmond Chapter and Support Group
- ◆ **Location:** 3rd Monday every month at 6 pm, in the Children's Hospital Auditorium at 2924 Brook Rd.
- ◆ **Contact:** Call the Richmond BIAV at (804) 355-5748 for more info!

### Saturday, March 7th, 2009

- ◆ **Event:** Brain Injury Association of VA 8th Annual Conference
- ◆ **Location:** Holiday Inn, Richmond Airport
- ◆ **Description:** This years theme is "Opening Doors: New Answers for a New Era." More info will be available soon! Check [www.biaav.net](http://www.biaav.net) for updates.
- ◆ **Contact:** Call the BIAV at 1-800-334-8443

### March 19th, 2009

- ◆ **Event:** Brain Injury Association of Massachusetts 28th Annual Conference
- ◆ **Location:** Best Western Royal Plaza, 181 Boston Post Rd. Marlborough, MA 01752
- ◆ **More Info:** [www.biama.org](http://www.biama.org), or contact Nicole M. Gofaire at (508) 475-0032 or (800) 242-0030

Not local to VA? That's ok! Most states have their own chapter of the Brain Injury Association.

If you go to [www.biausa.org/stateoffices.htm](http://www.biausa.org/stateoffices.htm), you'll find a list of all the states which have them with local contacts, and likely support groups and meetings listed throughout the state for TBI survivors.



If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please contact Matt Wetsel at 804-828-3703 or [wetselme@vcu.edu](mailto:wetselme@vcu.edu).

(Continued from Page 2, "Life and Work...")

Providers often hear their patients with brain injury, or the patients' family members, report the items on this checklist. As you can see, people with brain injury report a wide range of problems with sleep and fatigue.

Stress and pain are two important causes of fatigue. The following is a very helpful technique for reducing stress and managing pain. This technique has been used, found to be effective, and recommended by health care providers for many years.

**RELAXATION TECHNIQUE to practice**

- 1. Take a deep breath, let it out slowly, say "relax" to yourself.**
- 2. Extend your arms, make a fist, notice how tense your hands feel. Tell yourself "relax" and let your arms go limp. Notice how relaxed your hands feel now.**
- 3. Bring your head down toward your chest. Notice how tense your neck and shoulders feel. Say "relax" to yourself, and bring your head up VERY SLOWLY. Afterward, notice how relaxed your neck feels.**
- 4. Take a deep breath, hold it. Notice how tense your chest feels. Let your breath out slowly, saying "relax" to yourself. Afterward notice how relaxed your chest muscles feel.**
- 5. Close your eyes. Imagine you are lying on a beach, listening to the waves as they roll in and roll out. When you inhale imagine a wave rolling in. When you exhale imagine the wave going back out. Notice your breathing getting smooth and even, like the sound of the waves.**

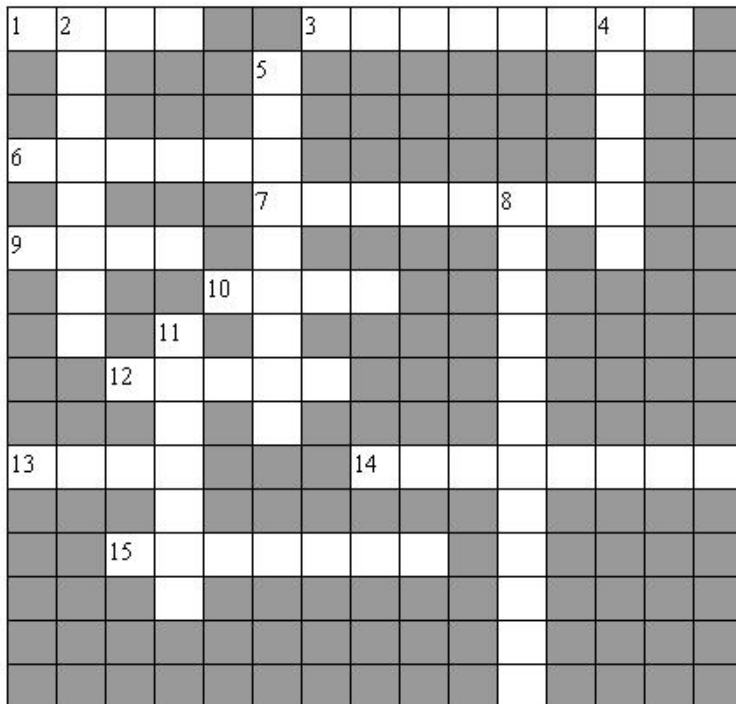
**Practice twice a day, when you are feeling tense, upset, or in pain.**

Here are some other ideas for helping with fatigue:

**Top Ten Tips for Energizing and Fighting Fatigue**

1. Try to stay up and active when the rest of the world is awake.
2. Rest if you need to, but don't take too many naps during the day, especially after 3 p.m.
3. Ask your doctor to help with medications if pain keeps you awake at night.
4. Eat healthy food to keep up your energy.
5. Breathe deeply, slowly, and evenly.
6. Don't do or focus on too much at once.
7. Avoid caffeine, especially in the evening.
8. Try relaxing activities right before bed time, like reading or watching television
9. If restless, find safe activities to use your energy. If restless at night, try boring activities such as watching cable news or reading a dictionary to become sleepy.
10. When working, settle into a quiet area with fewer distractions.

*This column was adapted from the Virginia Clubhouse Vocational Transitions Program Manual and Handouts, by Janet P. Niemeier, Jeffrey S. Kreutzer, and Shy M. DeGrace.*



**Puzzles can help you stay sharp! See if you can figure out all of the words! (Answers on Page 5)**

**ACROSS**

1. What Pat (with TBI Today) does best
3. If you had an injury you might be considered one
6. It gets colder this time of year
7. Finished on November 4th
9. When the leaves change colors
10. Sometimes you can't make it up
12. Help with remembering these are in this issue
13. Abbreviation for the program mentioned in 8 Down
14. It's ok if you can't always \_\_\_\_\_ someone's name
15. Families often provide this after injury

**DOWN**

2. Quite a few in November and December!
4. All TBI Today issues are available here
5. One of the subjects of the front page article
8. Everyone should check out the Brain Injury Family \_\_\_\_\_! (Page 6)
11. Sometimes a problem after injury



## CHAT WITH PAT

**Pat answers your personal questions about TBI with compassion and practical advice. However, advice from Pat's column should not substitute for consultation with a doctor or rehabilitation specialist. The identity of individuals submitting questions to "Chat with Pat" is kept strictly confidential.**

**DEAR PAT:** My husband was in a bad motorcycle accident about six months ago. Although he wore a helmet, the impact when he got thrown from the bike was pretty bad. His doctor told me he suffered a 'severe' brain injury. John was in a coma for 10 days and I was so scared that I was going to lose him. What a relief it was when he woke up! He then spent almost two months in the hospital getting rehab.

Rehab was really hard for both of us. It was hard work for him because he had to learn to do everything all over again, like walking and talking. John did so well, though, and I was very proud of him. At the same time, I was sad to see him struggle through it all. He was such a proud man. Anyway, John made lots of progress while he was in the hospital. You could see the improvements each day.

Finally the day came for him to come home! I was so excited. I knew there would be some adjustments but I sure wasn't prepared for what happened. The doctor said John probably wouldn't be able to go back to work for a year and he's restricted from driving. But, John didn't really understand what happened to him. He wanted to go back to work, drive, and ride his motorcycle! He still

has a lot of problems from the accident that he doesn't think are of concern. John's reasoning is off. I don't know how he came to certain conclusions but they somehow made sense to him. John is also pretty easily distracted and very forgetful. I'm afraid to leave him home alone because he may do something stupid and hurt himself. How can I get him to see that he needs help? We have gotten into a few fights already over what he can and cannot do. John thinks I'm being controlling, treating him like a kid.

Sincerely,

Frustrated Wife

### PAT'S RESPONSE:

Dear Frustrated Wife,

Taking care of a loved one with brain injury can be very frustrating. You obviously care a lot about your husband and want to keep him from getting hurt. Your job becomes more challenging when he is unable to see the difficulties. We call this lack of awareness. Lack of awareness is a common problem after brain injury. This limited awareness impacts judgment, often placing the person in unsafe situations. In addition, people with recent head trauma often have trouble concentrating, remembering what they are doing, or following along in conversations.

Awareness of difficulties after brain injury typically improves with time as the person heals. A number of people, however, seem to take longer getting their awareness back after having an injury. They may not be aware that problems with memory, motor skills, or slowed thinking are causing them difficulty. It is not unusual for such individuals to wonder what's wrong with *you* or others in their social circle. They could feel like there's nothing wrong with them and that nobody understands how badly they want to drive a car or return to work.

Helping to improve awareness is an important goal for you and your husband to work on together. First, you can help him to write down all the events related to

the accident and his hospital stay. This exercise will increase his understanding about how the accident has impacted his life and your family. Keep the list of events related to the accident nearby. He may come to realize the seriousness of his injury and how far he's come in the last months.

When the fact that he's had a brain injury has sunk in, John may be able to handle some gentle feedback from you. You could talk to him about things he may wish to work on in the future for getting better and staying safe. Asking questions is a good way to get people thinking about things. When you notice your husband having trouble with conversations, you may say something like, "You seem to have gotten lost. What was the last thing you remember us talking about?" Don't lose sight of the positive things he can do. Praise him often!

In the meantime, make sure you continue to carefully monitor your husband's activities and try to keep him safe from danger. Encourage him to try out different ways of doing things that may be less risky. You could help him create a list of projects around the house he can do that don't require climbing or using power tools. It is important to provide him with choices and a say in making decisions regarding his care when possible. With your enthusiasm and support, you can help improve his awareness of post-injury problems without ruining his self confidence.

Support groups are a great way to get feedback from others, if you wish to recruit more people in helping your husband become more aware. Your local Brain Injury Association of America likely has a list of support groups your husband may attend. To contact BIAA, you may call their family helpline (1-800-444-6443) or send them an e-mail at [family-helpline@biausa.org](mailto:family-helpline@biausa.org). The website for BIAA ([www.biausa.org](http://www.biausa.org)) provides links to state chapters and additional brain injury resources. You may also write BIAA for more information at 8201 Greensboro Drive, Suite 611, McLean, VA 22102.

*Questions for Pat or the FAQ column are welcomed.*

*Send them to: "ASK PAT" OR "FAQ"  
P.O. BOX 980542. RICHMOND, VA 23298-0542  
or e-mail: [jhmarwit@vcu.edu](mailto:jhmarwit@vcu.edu)*







**HAVE YOU  
MET MATT  
WETSEL?**

Matt Wetsel, B.S., B.A., is one of the latest additions to the Department of Physical Medicine and Rehabilitation at VCU. As a research specialist, he works with patients for recruitment, data collection, and follow-up interviews for research purposes on behalf of the VCU Traumatic brain Injury Model Systems (TBIMS) Project. Soon to enter its 20<sup>th</sup> year, the TBIMS Project provides crucial information to help better understand brain injury and recovery. Matt is also involved in a newer study which seeks to investigate the prevalence of headaches post-TBI, as well as research concerning

drugs which may improve the rate of recovery and function after brain injury.

Born in Harrisonburg, VA, Matt has lived in Richmond for 14 years. He graduated from VCU in May 2008 with majors in both Psychology and Religious Studies, with a concentration in Applied Psychology. At VCU, he was the founder and president of SEED, an eating disorder awareness and mental health advocacy group, and now serves as the group's advisor. With SEED, Matt has joined with other groups to lobby on Capitol Hill to improve federal legislation on mental health care for health care providers and insurance companies. Matt plans on continuing his education in graduate school, and is considering go-

ing into social work.

In his spare time, Matt enjoys cooking, building computers, spending time with friends, going to concerts, and is always looking for a good book to read. Sometime this winter, he hopes to visit his brother in Japan, who's currently teaching English in Nagoya.




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## VCU Brain Injury Family Intervention Project: A Unique Opportunity

Virginia Commonwealth University has developed the Brain Injury Family Intervention (BIFI) program directed toward both brain injury survivors and their family members. This program is available to families regardless of how long it has been since the brain injury. The purpose of the program is to strengthen families and promote long-term recovery after brain injury.

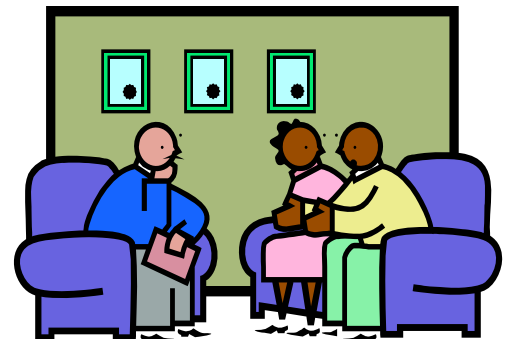
*As a TBI survivor, do you ever feel like your loved ones don't understand the difficulties of recovery?*

*As a family member, do you wish you had a better perspective on your loved one's recovery?*

Many families have described the program as very helpful. A decrease in depression symptoms and an increase in independence of the brain injury survivor are just a couple of the positive outcomes some participants in the BIFI have reported after finishing the program. Several types of families can participate in the BIFI program, and the program is free.

The sessions are conducted downtown in Richmond at VCU Medical Center. Currently, if your round trip is more than 120 miles, you may qualify for a travel reimbursement!

If you would like to participate in the BIFI program or learn more, please contact Taryn Stejskal at (804) 828-3701 or toll free at (866) 296-6904.



## Survivor Stories: The Axis Tilts

Recovery from a brain injury can often be made more difficult by all the emotions you experience afterwards. Sometimes people get depressed or frustrated as they go through recovery, and sometimes memories of the accident itself are very upsetting.

Some survivors find release through art, writing, or poetry. These are forms of self-expression which can communicate ideas that aren't always easy to put into plain words.

Our Survivor Story this time is from Jay Crandell, who has expressed his struggles in recovery through poetry. Jay is 24 years old, living in Gloucester, VA and is 2 years post-TBI. He was shot in Richmond by a stray bullet. Jay was an advertising student at VCU with one semester left to graduate when he was injured. He is still working hard on his recovery, and one day hopes to return to college to finish his degree.

The Axis Tilts by Jay Crandell

the axis tilts,  
and with burning claws the landscape rends its hues from the evening sky,  
embers cold and scattered below the streetlights.

we the soaring numbered dead,  
who step lightly into shining clouds  
and decompose nameless in heaps;

my aunts  
bronwyn, who died on christmas  
jennifer, taken atop Kilimanjaro on new year's day

and myself  
shot in the head july fourth.  
left to regain the ability to walk, to talk, to read, to eat solid food.

put up two fingers if you can hear me, jay  
one hundred days in the hospital  
a unique identifying poster atop each room's entrance, facing out.

we are the captains of otherwise empty ships  
straining against fickle and unfeeling currents,  
whose indiscernible patterns we cannot help but blindly trace;

we are as leaves in the cold winter air  
marionettes on the last gasps of uncountable billions  
and the wings of every butterfly that has ever lived.

so we will consecrate this instant;  
we will raise our glasses in a toast to aunt linda's 60th birthday  
and celebrate in the unfaltering onslaught of days our existence;

we will carve our names in the heaving oak  
letters writ large in the rended husks of million of cells  
their tiny souls whipping up towards heaven on the breeze;

and with the bones of those who came before us  
we will trace in the dust  
the design of our whirring clockwork.

***Want to share your survivor story? If so, please e-mail it to [jhmarwit@vcu.edu](mailto:jhmarwit@vcu.edu) or send by mail:***

***TBI Today  
P.O. Box 980542  
Richmond, Virginia 23298***



## Hey, I'd Like You To Meet... What's Your Name Again?

**Are you good with faces, but always forgetting people's names? A lot of people remember things they see more than things they hear – it happens to everyone. It can be even harder after a TBI, though. Here are some tips for remembering names when you meet people.**

### Pay Attention!

Stop whatever you're doing. Look at the person and find something unique or that stands out about them!

- What Color is their hair?
- Are they thin, heavy, short, tall?
- Facial features: nose, mouth, eyes? What stands out?

### Use it, *before* you lose it!

Use the person's name at least 3 times in the conversation.

It's easy!

- “Good to meet you, *John*.”
- “Have a good day, *Mary*.”

As you're getting to know someone, use their name when asking them questions, too!

- “Where do you work, *Jim*?”
- “Do you have any kids, *Terry*?”

### Remember!

Repeat their name in your head to yourself to help remember it.

### If you forget someone's name...

Don't worry! Most people will be understanding. Have a few lines ready in case you do forget...

- “Would you please refresh my memory? You're name is...”
- “I'm so sorry, I'm drawing a blank on your name.”
- “I remember we've met, but your name has escaped me.”

This article was taken from the book, *Memory Matters: Strategies for Managing Everyday Memory Problems* by Deborah West and Jan Niemeier. For more information about this book and other helpful resources, visit the National Resource Center for TBI website at [www.nrc.pmr.vcu.edu](http://www.nrc.pmr.vcu.edu) or call (804) 828-9055 to request a catalog.

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